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January 6, 2017

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Office of the Clerk of the House  
24 Beacon Street  
Room 145 – State House  
Boston, MA 02133

ATTN: Stephen T. James, House Clerk

In accordance with the provisions of line item 5920-3010 of Section 2 of Chapter 133 of the Acts of 2016, I am submitting a report on the Department's Autism Waiver Program for distribution.

Please feel free to contact me should you need additional information.

Sincerely,

A handwritten signature in cursive script that reads "Elin M. Howe".

Elin M. Howe  
Commissioner

**Charles D. Baker**  
Governor

**Karyn Polito**  
Lieutenant Governor



**Marylou Sudders**  
Secretary

**Elin M. Howe**  
Commissioner

# **DDS**

## **FY17 Autism Report**

### **December 23, 2016**

Massachusetts Department of Developmental Services





**Commonwealth of Massachusetts**  
**Department of Developmental Services**  
**Autism Waiver Program**  
**2016 Legislative Report**

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**All information contained in this report is current as of November 15, 2016.**



## I. Executive Summary

The Department of Developmental Services' (DDS) Autism Division respectfully submits this report in response to language contained in the FY 16 budget. Line-item 5920-3010 mandates the submission of this report as follows:

*On January 15, 2006, and every year thereafter, the secretary of health and human services shall file a report with the clerk of the house of representatives who shall forward the same to joint committees on education and health care financing on the status of the waiver application and on the operation of the waiver, once obtained. The report shall include, but not be limited to, a description of the number of children receiving services under the waiver, the race and primary language of the children served and their families, the types of services provided, and any available information pertaining to the effectiveness of the waiver.*

The information in this calendar year report was collected by the Autism Division and covers the Administration's activities related to the Autism Waiver Program from January 1, 2016 through November, 2016.

As a result of Chapter 107 of the Acts of 2005, the Department's Autism Division submitted an application to the Centers for Medicare and Medicaid Services (CMS) proposing a Federal Medicaid Waiver Program to serve young children on the autism spectrum. DDS received approval from CMS on October 1, 2007, allowing the Division to administer a three-year pilot Autism Waiver Program. In June 2010, DDS submitted a renewal application to CMS, receiving approval on October 1, 2010. The Renewal Autism Waiver Program allowed the Division to continue the Autism Waiver Program for an additional five years. Additionally, the Renewal Autism Waiver Program designated ten slots for three year olds transitioning out of Early Intervention - a statewide service available to families of children between birth and three years of age through the Department of Public Health (DPH). The renewal Waiver also built in a Step-Down Program after three years of intensive in-home supports that allowed families to receive behavioral consultation services and other ancillary supports until the child reached his/her ninth birthday.

CMS approved a waiver amendment in January 2013, increasing the program capacity to 157 participants and up to 205 unique children over the Waiver Year due to an increase in funding for the Autism Waiver Program at Legislative Mid-Year. CMS approved another waiver amendment in late November, 2013 to increase capacity based on an increase in funding for the Autism Waiver Program. The amendment increased the capacity for waiver year 3 retroactive to July 1, 2013 and increased capacity in years 4 and 5. The capacity for waiver years 4 and 5 was 220 point in time and 325 over the course of the Federal waiver year.

In September 2015 the Department submitted a renewal application to the Centers for Medicare and Medicaid (CMS). As part of the FY 16 budget the Autism Division received an increase in funding in the amount of \$500,000. These funds have allowed the Waiver program to expand to 260 children point in time and 385 participants during the course of the Waiver year which runs from October 1 to September 30<sup>th</sup>. The increase in participants from 220 in CY15 to 260 currently occurred progressively over the first half of 2016. The program has expanded its reserved capacity for three years olds from ten children to twenty children.

To date the Autism Division has held seven Open Request Periods since the Autism Waiver Program began in 2008: October 2008, October 2010, April 2012, October 2013, November 2014, October 2015 and October 2016 which has been completed at the time of this report production. These Open Request Periods have consistently resulted in high numbers of interested families as detailed in the table on page 4.



Year	Number of Families Interested in Autism Waiver Program
2008	1,200
2010	600
2012	800
2013	800
2014	750
2015	734
2016	817

The Massachusetts Autism Waiver Program is distinguished from many other national programs in that it is an entirely self-directed program, meaning that families play the key role in hiring staff and identifying the services and supports they wish to have in place for their child. There are no other completely self-directed Autism Waiver Programs for children in the nation. The Waiver provides Expanded Habilitation, Education services (positive behavioral supports, social and communication-based interventions) and related support services such as community integration activities and respite.

Each Autism Waiver Program participant works with a staff of one DDS Autism Clinical Manager (or "Targeted Case Manager") that provides overall oversight and assistance to families and one Autism Support Broker who helps families design and maintain their services and expenditures. The staff works with families to develop an in-home support plan with the goal of addressing the individual child's needs in the areas of communication, socialization, basic skill development and adaptive behavior. Additionally, the family is offered other ancillary services (safety equipment, respite and community integration activities) and related supports. During the first three years of participation (the "intensive phase" of the Program), families are given access to a budget of up to \$25,000 each year. The majority of these funds are directed toward the positive behavior support program in the home and in the natural environments of the participant; up to \$5500 of the annual budget is available for ancillary services. After the three years of intensive services, the family transitions into the Waiver's Step-Down Program which is intended to allow the parent to take over the in-home strategies learned during the intensive phase with support from both a Behavioral Consultant and Direct Support staff to continue to assist the family. This Step-Down Program is available until the child's ninth birthday; families are given access to a budget allocation up to \$7500 on an annual basis.



## **II. Background on the Autism Waiver Program**

The Autism Division (the Division) of the Department of Developmental Services (DDS) currently administers an Autism Spectrum Disorder Home and Community Based Waiver Program for Children (the Waiver). The Waiver is a program for children under the age of nine with an autism spectrum disorder and who meet all the eligibility criteria required for entrance into the Waiver.

For participants, the major service for the first three years of the Waiver Program is Expanded Habilitation, Education. The goal of this service is to help support children with autism by addressing the significant deficits they face in the areas of behavioral, social and communication skills. The service consists of in-home and community-based one-to-one interventions developed and monitored by trained clinicians. Expanded Habilitation includes, but is not limited to, positive behavior supports such as Applied Behavioral Analysis (ABA), developmental and relational models such as Floor Time and communication models. The goal of the Expanded Habilitation, Education Service is to help children develop basic adaptive skills, elementary verbal skills and appropriate interactive and play skills.

The Waiver Program uses a service delivery model called Participant Direction in which the parent takes the lead in designing the program and selecting service providers based on the child's assessed level of need. The parent works closely with the Autism Waiver Program staff to develop a support plan that outlines the goals and objectives for the child, while also looking at the child's strengths and areas of concern. Each family receives day-to-day support from an Autism Support Broker at one of the seven DDS funded Autism Support Centers, and programmatic oversight and problem solving assistance from a Targeted Case Manager at the Autism Division. This support plan translates into a coordinated set of in-home services with a budget that relates to the costs of the services. During the "intensive portion" (the first three years of the Program) each family has an available annual allocation of \$25,000. The budget for those within the intensive portion of the Waiver also includes the availability of ancillary supports such as safety equipment, respite and community integration activities. Five thousand five hundred dollars (\$5,500) can be allocated toward these ancillary supports.

After three years of intensive services, the family transitions into the Step-Down Program. The Step-Down Program supports are up to a total budget of \$7,500 per family and include Behavioral Consultation along with all ancillary services to help the family continue the in-home program on their own. This portion of the Autism Waiver Program is parent-driven with help from a Behavioral Consultant and can continue up until the child's ninth birthday.

In the event that a child is turning nine within the service year, the Waiver staff prorates the \$25,000 budget to reflect the number of months that the child is eligible for the Program. In these cases, the staff prorates the in-home services portion of the budget. The family may access the entire \$5,500 allocation for ancillary supports to help meet the health and safety needs of the child. These needs often include installing locks, alarms, and home adaptations such as fences.

# **Information on Active Autism Waiver Participants**



### III. Information on Active Autism Waiver Participants

As this report is based on a calendar year (CY) cycle (per line-item 5920-3010), information to follow is based on participation within the Autism Waiver Program starting in January 2016 and ending as of November 15, 2016.

#### Enrollment Updates for the Autism Waiver

Since January 2016, 77 new children were determined eligible for services and a total of 319 children participated in the Waiver Program. As of November 15, 2016, there are 260 currently children enrolled in the Autism Waiver Program. All budget details are based on the 319 children served across the 2016 calendar year.

#### Autism Waiver Program Eligibility Data (Calendar Year 2016)

The Division processed 224 Waiver applications in CY 16. The processing of applications includes determining which children on the list are over the age of nine, are not covered by MassHealth Standard and/or are not eligible for MassHealth Standard (making them ineligible) as well as making repeated attempts to connect with eligible families (by phone, email and mail) who have been unresponsive.

The processing of applications also includes a review for clinical eligibility either by collecting records to verify the child's existing DDS eligibility or by finding the child to be DDS eligible at the conclusion of the DDS children's eligibility process. Following the DDS eligibility confirmation or determination, the Division performs two clinical assessments that measure the child's deficits in the areas of socialization, communication and behavior. If the child was not found to meet the criteria for clinical eligibility, (in CY 16, 11 children did not) families are sent a letter notifying them that their child cannot participate in the Waiver Program. If a child is found to meet the clinical eligibility criteria (77 children in CY 16), the family is approved for enrollment into the Program. The following table references the 224 Waiver applications processed.

Waiver Applicants Processed Within CY 2016		Total
Determined Eligible for the Program		77
Age Ineligible		40
MassHealth Ineligible		30
Voluntary Withdrawals (Family withdrew or DDS could not contact)		48
Determined Clinically Ineligible		11
Deceased		1
Eligibility in Process		17
<b>TOTAL</b>		<b>224</b>

**Active Participants in the Autism Waiver Program-January 1, 2016- November 15, 2016**

**Male/Female Distribution Information**

In Calendar Year 2016, about 78% of participants were males and 22% were females and this follows the national trend that indicates boys are much more prone to be diagnosed with an autism spectrum disorder than girls.

Gender of Participants Served in CY 2016		Total
Male		247
Female		72
Total		319

**Diagnostic Information**

Approximately 5% of the children served in the Waiver have identified co-morbid conditions. These conditions include metabolic, genetic, physical, and psychiatric disorders. The rate of psychiatric diagnosis is low and does not typically occur in young children; this information is rarely present in the record. In some cases, other conditions are more salient than the autism, requiring multiple hospitalizations and intensive nursing. Scheduling of in-home services can be more challenging when dealing with these conditions compared to cases where autism spectrum disorder is the sole diagnosis.

Diagnostic Information for Participants Served Calendar Year 2015		Totals
Autism & PDD (Pervasive Developmental Disorder)		263
RETT Syndrome		1
Autism & Other Co-Morbid Conditions - both Health and Developmental Issues		55
Total		319



## Cultural and Linguistic Information

Language Information for Participants	
Language	# of Participants
English	198
Spanish	79 (34 require interpreter)
French	2 (1 requires interpreter)
Portuguese	13 (1 requires interpreter)
Haitian Creole	8 (0 require interpreter)
Vietnamese	7 (1 requires interpreter)
Mandarin	2 (2 require interpreter)
Russian	1 (0 require interpreter)
Cape Verde Creole	2 (2 require interpreter)
Cantonese	2 (1 requires interpreter)
Egyptian Arabic	1 (0 require interpreter)
Arabic	2 (1 requires interpreter)
Bengali	1 (0 require interpreter)
Indian	1 (1 requires interpreter)
<b>Total</b>	<b>319 (44 requiring interpreters)</b>

Cultural Information for Participants	
Ethnicity	# of Participants
Caucasian	114
Latino/Hispanic	100
African American	43
Portuguese	18
Dominican	4
Haitian	8
Middle Eastern	11
Chinese	4
Vietnamese	7
Moroccan	4
Cape Verdean	2
Russian	1
Indian	1
Puerto Rican	2
<b>Total</b>	<b>319</b>

The 319 children served in the Waiver Program in CY 16 represent a wide range of linguistic and cultural backgrounds as identified by the Autism Clinical Managers and Parents/Guardians. If a family requires the use of an interpreter, the Division provides interpreters and translations at no charge.



**Breakdown of Age of Participants - Age as of November 15, 2016**

The Program serves a wide range of ages of children between ages two and nine.

Age of 319 Participants as of 11/15/16			
Age 2	0	Age 6	76
Age 3	12	Age 7	51
Age 4	39	Age 8	59
Age 5	46	Age 9	36

**Sibling Data of Participants**

January 1 through November 15, 2016

Sibling Information for Participants	
Siblings:	
Breakdown Totals (status of other children)	
Number Siblings Pairs Enrolled: (non-twins)	Families: 15
Number of Sibling Pairs Enrolled: (twins)	Families: 12
Number of Siblings Pairs Enrolled: (twins + non twin sibling)	Families: 3
TOTAL (non-duplicative count):	Families: 30

### City and Town Distribution of the 319 Participants

The Waiver Program enrollment is heavily weighted with children coming from major cities like Worcester (26), Boston (37), Springfield (31).

Town	#	Town	#	Town	#	Town	#	Town	#
Adams	1	Dennis	1	Hyde Park	2	North Attleboro	1	Springfield	31
Agawam	2	Dracut	1	Jamaica Plain	3	Northborough	2	Stoughton	1
Arlington	1	Duxbury	1	Lawrence	4	Norwood	4	Swampscott	1
Attleboro	4	East Boston	4	Leicester	1	Oxford	1	Taunton	6
Auburn	2	East Hampton	2	Leominster	3	Peabody	3	Waltham	1
Barre	2	Everett	7	Littleton	3	Pittsfield	1	Wareham	2
Bedford	1	Fall River	7	Lowell	4	Plymouth	1	Watertown	1
Bellingham	1	Fitchburg	1	Lynn	7	Quincy	2	Webster	1
Beverly	1	Florence	1	Lynnfield	1	Randolph	1	Wellfleet	1
Boston	21	Framingham	6	Malden	4	Revere	3	West Bridgewater	3
Bridgewater	2	Franklin	1	Marlborough	2	Rosindale	3	West Roxbury	3
Brighton	1	Gloucester	2	Mattapan	5	Roxbury	4	West Springfield	1
Brimfield	1	Granby	1	Mattapoisett	1	Salem	2	Westborough	1
Brockton	7	Hampden	1	Medford	2	Salisbury	2	Westfield	6
Burlington	1	Haverhill	3	Melrose	1	Seekonk	1	Weymouth	1
Buzzards Bay	1	Holden	1	Methuen	1	Shrewsbury	1	Worcester	26
Cambridge	3	Holliston	2	Milford	3	Shirley	1		
Chelsea	1	Holyoke	6	Millville	1	Somerville	2		
Chicopee	9	Hopedale	1	New Bedford	19	South Boston	3		
Clinton	3	Hudson	1	Newton	2	South Yarmouth	1		
Dedham	1	Hyannis	1	North Andover	1	Southbridge	7		
<b>Total:</b>									<b>319</b>



### Disenrollment Information

Between January 2016 through November 15, 2016, 60 children were disenrolled from the Autism Program. 37 children left the Program as scheduled on their ninth birthday; however, 9 children left due to ineligibility for continued MassHealth Standard coverage.

Disenrollment Information for Participants	
Reason for Disenrollment	Number
Turned Nine	37
Moved Out of State	1
Residential Placement	1
Lost MassHealth Standard	9
Not Utilizing Services	3
Voluntary Withdrawal	7
Lost Diagnosis	2
<b>TOTAL</b>	<b>60</b>

### Open Enrollment

#### Male/Female Distribution Information

About 80% of applicants were males and 20% were females and this follows the national trend that indicates boys are much more prone to receiving an autism diagnosis than girls.

Gender of Open Enrollment Applications CY 2016		Total
Male		655
Female		162
<b>Total</b>		<b>817</b>



### Cultural and Linguistic Information

The 817 applicants for the Waiver Program in CY 16 represent a wide range of linguistic backgrounds as identified by the and Parents/Guardians. The most frequently spoken languages other than English are Spanish (16%), Chinese (3%) and Portuguese (3%).

DDS modified the document for the October Open Request period, to clarify the questions about the families' preferred language for both oral and written communication. To facilitate access, DDS has also expanded its capacity to provide both oral and written translations and has added a telephonic interpretation line. DDS has clarified in its written waiver materials that if a family requires the use of an interpreter, the Division provides interpreters, translations and telephonic access at no charge to the family.

The percentage of applicants speaking a language other than English increased by 6% as compared to CY 15 and the number of languages spoken among the pool of applicants (17 languages in CY 16 as compared to 13 in CY 15) also increased.

Language Information for CY 16 Applicants			
Language	# of Applicants	Language	# of Applicants
English	607	Burmese	1
Spanish	128	Hmong	1
Chinese	23	Kiswahili	1
Portuguese	21	Korean	1
Arabic	9	Nepali	1
Vietnamese	8	Thai	1
Khmer	4	Turkish	1
Creole	3	Russian	1
Amharic	2	No language identified	2
ASL	2		
		<b>Total</b>	<b>817</b>

**Breakdown of Age of Open Enrollment Applicants**

Ages of Applicants			
Age 1	7	Age 6	124
Age 2	102	Age 7	89
Age 3	141	Age 8	50
Age 4	164	Age 9 and older	6
Age 5	140	Total	817

**Sibling Data of Open Request Applicants:**

Siblings:		Breakdown Totals (status of other children)
Number Sibling Pairs or Groups: (non-twins)		Families: 28
		13 sets of brothers
		13 brother/sister pairing
		0 sister/sister pairings
		2 three children groups,(2 boys and 1 girl and 3 boys)
Number of Sibling Pairs: (twins)		Families: 7
		6 sets of twin boys
		1 sets of boy/girl twins
		0 sets of twin girls
		Families: 1
Number of Sibling Triplets:		1 set of triplet boys
		Families: 1
Number of Twins/Siblings:		1 set twin boys plus sibling sister
		Families: 1
Total (non-duplicative count):		Families: 37



### City and Town Distribution of the Open Enrollment Applicants

Applicants are from 162 communities with a heavy weighting coming from major cities like Boston, Springfield, Lawrence, Lowell and Worcester.

Town	#	Town	#	Town	#	Town	#	Town	#	Town	#	Town	#	Town	#
Boston	119	Westfield	8	Canton	3	Bellingham	2	Pepperrell	2	East Taunton	1	Middleborough	1	Tolland	1
Springfield	74	Agawam	7	Newton	3	Boxborough	2	Reading	2	East Wareham	1	Millbury	1	Townsend	1
Lawrence	42	Marlborough	6	Newton	3	Braintree	2	Russell	2	Edgartown	1	North Brookfield	1	Uxbridge	1
Lowell	40	Plymouth	6	Leominster	3	Brewster	2	South Dartmouth	2	Fairhaven	1	North Chelmsford	1	Wellesley	1
Worcester	37	Webster	6	Ludlow	3	Danvers	2	South Hamilton	2	Forestdale	1	North Easton	1	West Warren	1
Chicopee	20	Dracut	5	Medford	3	Douglas	2	Sunderland	2	Halifax	1	Northborough	1	Westwood	1
Quincy	18	Haverhill	5	Medway	3	East Longmeadow	2	Wakefield	2	Hampden	1	Northbridge	1	Whitman	1
Taunton	17	Westborough	5	Methuen	3	Easthampton	2	Ware	2	Hanover	1	Orleans	1	Winthrop	1
Holyoke	16	Billerica	4	Norwood	3	Fiskdale	2	Wareham	2	Hanson	1	Princeton	1		
Lynn	15	Fall River	4	Pittsfield	3	Foxboro	2	Wellfleet	2	Holliston	1	Raynham	1		
New Bedford	15	Gardner	4	Saugus	3	Franklin	2	Westford	2	Hudson	1	Rockland	1		
Cambridge	14	Hopkinton	4	Shrewsbury	3	Gloucester	2	Belchertown	1	Hull	1	Rowley	1		
Everett	14	Lexington	4	Waltham	3	Granby	2	Blackstone	1	Kingston	1	South Dennis	1		
Frammingham	14	North Adams	4	Watertown	3	Greenfield	2	Brookline	1	Lee	1	South Hamilton	1		
Revere	13	Peabody	4	Weymouth	3	Groveland	2	Charlton	1	Leicester	1	Somerset	1		
Malden	11	Randolph	4	Wilbraham	3	Hyannis	2	Chelmsford	1	Lenox	1	Spencer	1		
Fitchburg	10	South Hadley	4	Woburn	3	Lunenburg	2	Cheshire	1	Littleton	1	Stoneham	1		
Somerville	9	Southbridge	4	Arlington	2	Marblehead	2	Clinton	1	Longmeadow	1	Stoughton	1		
Brockton	8	Amherst	3	Ashland	2	Marshfield	2	Dartmouth	1	Mansfield	1	Sturbridge	1		
Chelsea	8	Beverly	3	Attleboro	2	Milford	2	Deerfield	1	Maynard	1	Swampscott	1		
Salem	8	Bradford	3	Auburn	2	Newburyport	2	Dudley	1	Medfield	1	Swansea	1		
West Springfield	8	Burlington	3	Bedford	2	Orange	2	East Bridgewater	1	Melrose	1	Tewksbury	1	Total:	817



#### IV. Autism Waiver Program Provider Information

In CY 16, the Autism Waiver Program allocation is approximately \$5.0 million. This appropriation includes approximately \$1.5 million necessary to cover the administrative costs of the Program. It also includes the Financial Management Service's (FMS) monthly fees-per-participant which is an additional cost of approximately \$302,881 as of November, 15, 2016.

The CY 16 administrative budget is broken down as follows:

- \$900,000 – Personnel Costs: 18 Autism Support Brokers
- \$250,000 – Personnel/Operational Costs: 6 supporting DDS Autism Clinical Managers (*a 6th Autism Clinical Manager was added in October, 2016*).
- \$100,000 – Other Personnel Costs: Necessary Central Office Unit personnel to administer, provide quality assurance and support billing and claiming activities

The budget for FMS fees is broken down as follows:

- \$33,000-\$33,600 per month (Approximately \$302,881 for CY 16) – Fiscal Management Service (FMS) monthly per participant fee: Covers staff time related to processing timesheets, payments and provider credentials.

At the outset of the Autism Waiver Program, a major outreach effort took place to locate and qualify potential providers of services offered through the Program. This outreach included: all Early Intervention providers in the Commonwealth, all Special Education Departments in schools districts across the state, all major providers of autism and related services and Colleges/Universities with majors/minors in the disability education field. The Autism Support Brokers do a concerted outreach effort to try and obtain new providers about every 12-18 months or as needed to meet an individual family's needs.

All identified potential providers were added to a Master Provider List (MPL) that consists of Agencies, Independent Contractors and Employees. As of November 15, 2016, the list of unique providers totaled 961. The MPL, which is an online web-based listing, is available to families in their geographic region and is utilized by the Autism Support Brokers at initial meetings with every new family.

**Providers by Service Information:**

Due to the flexibility of the Waiver Program's service design, many of these providers are new to DDS.

Provider Totals (As of November 15, 2016):

Service Type	Description of Provider Duties	Total #
Expanded Habilitation, Education: Senior Level Therapists	Responsible for the creation and oversight of the in-home support plan	255
Step Down Program ( <i>after 3 years</i> ): Behavioral Consultants	Responsible for providing technical assistance for the continuation of the in-home support plan	53
Expanded Habilitation, Education: Therapists	Responsible for carrying-out the in-home plan with the child on a one-to-one basis	367
Expanded Habilitation, Education: Direct Supports	Responsible for carrying-out the in-home plan with the child on a one-to-one basis	488
Habilitation, Community Integration	Responsible for helping the child to participate in activities and other programs provided in community settings	280
Family Training	Responsible for teaching families about a variety of topics based on needs, such as autism in general, working on safety or reinforcing the work of the in-home service providers	166
Respite	Responsible to provide respite care of the child, allowing the parent or guardian to get out of the house for a short period of time	501
Total Number of Providers Credentialed by Service Type		2,110
Total Unique Number of Credentialed Providers		961



### Participant Budgets by Service Type

The majority of service provision funding is spent on the Waiver's intensive in-home support program, Expanded Habilitation Education. Children receive an average of between 6 to 10 hours a week of intensive in-home support services provided by a variety of therapists and based on a set of goals developed with input from the parent/guardian. Families also prioritize respite and community integration as important services.

Participant Budget Data by Service Type	
<i>Point-in time number captures budget totals as of November 15, 2016</i>	
Service	Amounts
<i>(total budgeted for 319 participants)</i>	
<i>(rounded in thousands)</i>	
Expanded Habilitation, Education	\$4,249,862
Behavioral Consultation (Step Down)	\$281,885
Habilitation, Community Integration	\$83,098
Family Training	\$9,314
Respite (includes related workers comp costs)	\$268,000
Home/Vehicle Adaptations and Adaptive Aids	\$64,657
Goods and Services/Homemaker	\$88,306
<b>TOTAL Budgeted Service Dollars:</b>	<b>\$5,045,122</b>

### Service Amounts per Participant: Covers budget information for participants from January 2016 - November 15, 2016

Of the 319 Waiver Program participants, 182 children received over \$20,000 worth of services and supports, while another 54 receive services and supports between \$10,000 and \$20,000. There were 13 participants with budgets under \$10,000 and the majority of these participants turned 9 during CY 16 and therefore had prorated budgets to reflect their shortened time in the program. Most participants in the Program are also receiving ancillary services such as goods and services to purchase safety equipment, home/vehicle adaptations and community integration services in order to increase the child's ability to participate in community activities. Most families are also receiving a respite service, providing critical relief to families. In CY 16, 70 children were enrolled in the Step Down program, receiving \$7,500 of supports that includes Behavioral Consultation.



Number of Participants in various Budget Categories		
Service	Number of Participants	Amounts (rounded into dollar bands)
Overall Budgeted Amount	182	\$20,000 - \$25,000 (Max is \$25K)
Overall Budgeted Amount	54	\$10,001 - \$19,999
Overall Budgeted Amount	13	\$10,000 or below- includes prorated budgets
Step Down Budgeted Amount	70	\$7,500 or below
<b>Total</b>	<b>319</b>	
<b>Service</b>	<b># of Participants</b>	<b>Amounts (rounded dollar bands)</b>
Expanded Habilitation, Ed	153	\$20,000 - \$25,000 (Max is \$25K)
Expanded Habilitation, Ed	53	\$15,001 - \$19,999
Expanded Habilitation, Ed	31	\$10,001 - \$15,000
Expanded Habilitation, Ed	12	\$10,000 or below--includes prorated budgets
Behavioral Consultation (Step Down)	70	\$7,500 or below
<b>Overall Total</b>	<b>319</b>	<b>Exp. Hab, Ed &amp; Behavioral Consultation</b>
<b>Service</b>	<b># of Participants</b>	<b>Amounts (rounded dollar bands)</b>
Total Ancillary Services	89	Under \$2,500
Total Ancillary Services	84	\$2,501 - \$5,500 (Max is \$5,500)
	46	No Ancillary Services/Or in Step Down
<b>Total</b>	<b>319</b>	

## **VI. Measuring Programmatic Outcomes**

The Federal CMS review of the Autism Waiver Program requires internal oversight and program monitoring on at least a quarterly basis. As part of the renewal effort an evidence package was submitted to CMS and approved by CMS.

## **VII. Next Steps/New Developments**

The Department of Developmental Services' Autism Division adopted a new approach with the Autism Waiver eligibility process following the April 2013 Open Request period. An annual open request period occurs on an annual basis the last two weeks of October. There is now a pool of eligible applicants waiting to fill the spots that become available as other participants age out or leave the program for unplanned reasons, (as of this report we have seven children waiting). This helps to keep enrollment more consistent. Each Clinical Manager also works a caseload of eligibility cases on an ongoing basis to keep the pool deep enough to fill the opening slots.

The Autism Waiver program has implemented a transition process post termination of the waiver services to increase the knowledge of the family and child's needs when the case is returned to the DDS field Area Office. DDS Area staff are invited to a transition meeting to insure a smooth hand-off for the family.

The Autism Waiver Program works to insure that children receive state plan ABA if the family is interested in receiving this service in addition to the waiver services. The addition of state plan ABA has helped the child transition out of the Autism Waiver Program. Accessing the state plan benefit has not diminished the interest in the Autism Waiver program based on the increase in the number of open requests received in October, 2016. The continued interest in the program reflects ongoing need for additional funding. Additionally, there are increased costs associated with providing the services as rates increase. It is clear that the Autism Waiver program continues to meet the needs of children and families.

The Division remains encouraged and driven by the many children in the Program who have surpassed their goals and continue to thrive in their In-Home Programs. Several children now have language skills that had none when they first started in the Autism Waiver Program. Others are demonstrating less behavioral issues due to the intensive in-home behavioral programs provided by in-home staff. Still others have mastered basic skills like eating at the table and using the bathroom consistently, improving the lives of not only the child, but also the caregivers and siblings. The demand for the Program remains high and it is clear that it addresses an important need for young children with autism spectrum disorders – a demand the Division is committed to meet.



## **VIII: Legislation**

### **Chapter 107 of the Acts of 2005, An Act relative to federal reimbursement for services for children with Autism, Approved by the Governor, October 5, 2005**

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

*The secretary of health and human services shall, within 3 months of the effective date of this act, apply to the federal Centers for Medicare & Medicaid Services for a home and community-based services waiver under section 1915(c) of the federal Social Security Act, 42 U.S.C. section 1396(n), to allow eligible children with autism spectrum disorder to receive waiver services to support the children in their homes and communities.*

*The waiver application shall provide services for children with autism spectrum disorder who are institutionalized or at risk of institutionalization. Autism spectrum disorder includes the following disorders as defined in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV-TR, 2000): autistic disorder, Asperger's disorder, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Rett's disorder.*

*The waiver application shall include intensive in-home intervention services for children with autism spectrum disorder, and any other services determined appropriate to support children with autism spectrum disorder in their homes and communities.*

*The waiver application shall specify the required credentials for the providers of services covered by the waiver, including credentials required for supervisors of direct care providers and credentials required for direct care providers.*

*The waiver application shall ensure that the process and procedures for applying for waiver services are fully accessible to families of children with autism spectrum disorder who are from linguistically and culturally diverse communities.*

*Services under the waiver shall be coordinated with services provided by school committees under chapters 71B and 111G of the General Laws. This section shall not affect or limit a school district's ability to obtain Medicaid reimbursement for school-related health services, or affect or limit a school district's responsibility to provide all services, including home-based services, required pursuant to said chapter 71B, 20 U.S.C. section 1400 to 1487, inclusive, and 29 U.S.C. section 794.*

*On January 15, 2006, and every year thereafter, the secretary of health and human services shall file a report with the clerk of the house of representatives who shall forward the same to the joint committees on education and health care financing on the status of the waiver application and on the operation of waiver, once obtained. The report on the operation of the waiver shall include, but not be limited to, a description of the number of children receiving services under the waiver, the race and primary language of the children served and their families, the types of services provided, and any available information pertaining to impact and effectiveness of the waiver.*